

NYSTAGMUS NETWORK (UK) NETLETTER
March 2006

YELLOW SUBMARINE

NN is in Liverpool's London Road on Tuesday, May 23, for a one day special on nystagmus. Find out what it's like to have nystagmus, what you can do about it, what research is going on and meet people with nystagmus.

This one day seminar entitled "Nystagmus in children and young people" is open to all. For further information, contact Gillian McLaren at the RNIB either by email gillian.mclaren@rnib.org.uk or phone 0151 298 3224.

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THE STREET OF SHAME

Well, our Focus newsletter is not quite Fleet Street, but being editor could just give you the experience you need. Current editor Tamsyn is saying farewell after the June issue ahead of becoming a mum. So, we're looking for someone to take over and help produce the quarterly printed face of the Nystagmus Network.

Ideally, we are looking for someone with both editorial and layout skills. But we'd like to hear from you if you have just one of those skill-sets, or simply think you can convince us you're up to the job. This is an unpaid post, but the experience will be invaluable. Please contact John Sanders at eyesitejs@msn.com for more details.

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Information from Contact a family and RNIB

Contact a family has published the "Contact a Family Rare Eye Conditions Directory". It is available for £15.00 from www.cafamily.org.uk

The RNIB have revised two publications

Insight-Helping children and young people live and learn with sight problems

NB (formerly New Beacon) The sight loss and eye health magazine

Sample copies are available from cservices@rnib.org.uk

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MS and Nystagmus

Caroline Fisher who has MS and acquired nystagmus would like to contact anyone who has a similar condition caroline@carolinefisher.wanadoo.co.uk

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TAKE A WALK ON THE WILD SIDE (OF THE WEB)

“If you're looking for traditional support or ideas on how to cope with this terrible affliction then, um, this may not be the place for you. We're here to explode some of those media notions that being blind is some kind of living death, a mystical twilight state or a call to bravely climb mountains.”

That's the introduction to the website <http://www.blindkiss.com/> and it pretty accurately sums up what BlindKiss is all about. Blogs and bites sit alongside articles such as “Top 10 ways to attract a blind man” and “Office Romance”. Enough said really.

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PROMISING PROGRESS

We often pass on requests from researchers looking for volunteers, but it's not often that we can update you with encouraging news from these projects. For one thing, they take a long time to complete. For another, much research into nystagmus is aimed at increasing our long term understanding of the condition and is not necessarily focused on finding an immediate treatment or cure.

During March, though, we had some positive news from researchers in Leicester about their pilot project for treating congenital nystagmus with drugs. You may recall that we were looking for subjects to take part in this project all last year, so thanks to everyone who volunteered.

The research team have just reported that the initial findings of the pilot are promising. However, since parts of the results are not yet fully analysed, they are not able to provide more detailed information at the moment.

Nonetheless, the results are encouraging enough for the Leicester team to start preparations for a larger study. They are now examining people with nystagmus with a view to including them in the next study. If you are interested please contact Rebecca McLean (phone: 0116 2586290 or e-mail rjm19@le.ac.uk).

Volunteers should be aged over 18, have congenital nystagmus and be able to travel to Leicester. The research has been approved by the relevant Hospital ethics committees.

We'll keep you updated on this and other research through this Netletter and our Focus newsletter.

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SCHOOL FINDER

Justin Mullins' young daughter is visually impaired. Justin thought it would be a fairly straightforward matter to find a list of schools in the UK with resources for VI children. But no, he discovered that no such list exists.

So, after much painstaking research, he set up his own website at <http://www.helpinsight.org.uk/Contact.htm>. The website lists all the schools Justin has found so far which are either schools solely for VI children or mainstream schools with attached VI support units.

The list is not yet complete – for example it covers only England, not Wales, Scotland and Northern Ireland at the moment.

Justin hopes that making this information public will help to improve the quality of education for visually impaired children. He has made every attempt to make the website as accurate and up-to-date as possible. But inevitably errors will creep in, so please let him know of any you find.

And if you know of any schools that should be included on this site but aren't, drop him an email at feedback@helpinsight.org.uk

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Contributions

Please send contributions, ideas or links for the NetLetter to Gill Taylor at gill@taylorsonline.com.